

## Research paper

# Methodological limitations posed by the Data Protection Act in research involving medical practitioners: a study into doctors' career and retirement choices

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## ABSTRACT

**Aims** This paper aims to highlight the obstacles typically encountered as a result of the Data Protection Act when using medically qualified practitioners as research participants.

**Method** As part of the 'Doctors' Career and Retirement Choices' study, 47 medically qualified individuals have been interviewed, 21 have participated in a questionnaire pilot study and 534 in the main questionnaire study. The limitations encountered concerning data protection throughout the research, have been logged and are presented in this paper.

**Results** During the study's progress, a number of difficulties arising from The Data Protection Act have been found relating to doctors' participation in the research. They largely include difficulties in

accessing doctors' contact details, problems with individual interpretation of the Act, and anxiety around the sharing of data being detrimental to the study. Solutions to the difficulties encountered include recruiting samples via websites, holding individual contact details in the public domain and via colleagues' personal networks.

**Conclusions** While data protection presents obstacles to conducting research where doctors are the key sample group, there are effective methods of overcoming them.

**Keywords:** career choices, Data Protection Act, medical practitioners, methodological limitations, retirement choices

## Introduction

This paper highlights the difficulties that can be encountered with respect to data protection when conducting research using medical staff as participants.<sup>1</sup> The North Western Deanery has initiated the 'Doctors' Career and Retirement Choices' study in response to the nationwide problem of retaining doctors at the earliest and latest stages of their careers. The study aims to investigate factors influencing the career decisions of 1993–95 graduates from a university medical school, to gain information on the career

paths of a representative sample of graduates, and to investigate why medical graduates leave medicine and/or the region in which they have studied to practice elsewhere. The study also involves consulting with medical professionals aged 55 years and over, with the aim of exploring decisions made around continuing to work versus taking early retirement, and focuses upon how they can be retained in employment past the age of 55. The study aims to produce recommendations for how graduates and

consultants over 55 can be retained in both the profession and the region.

The specific 'graduate' participant group was selected to provide a sample of trainee grade doctors who are 8–10 years past graduation and have sufficient experience of training to enable their informed response to research questions about the reasons for career decisions. As 55 is the age at which doctors can opt to take 'early' retirement, this has been identified as an appropriate lower age limit to impose upon the 'late stage' participant sample. Both samples derive from North West populations (The North West region is, for the purpose of the study, defined as the area formerly covered by the North West Regional Health Authority).

Throughout the research a number of limitations have been encountered, overwhelmingly with The Data Protection Act. This is despite the fact that under section 33 of the Act, personal data may be used by researchers where the anonymity of 'data subjects' is protected in the study's results. This has created difficulties with the progression of the study. This paper will explore these limitations and explain how they were rectified for the benefit of other researchers working within similar fields.

## Methods

'Stage 1' of the study involved interviewing 47 medically qualified doctors from two different sample groups between January 2004 and January 2005, either by face-to-face or telephone interview methods. One sample group comprised doctors who graduated from a university medical school between 1993 and 1995, and the second group was medically qualified hospital consultants who were either currently practicing in the North West region or had been doing so in their last post prior to retirement. 'Stage 2' of the study was to carry out a questionnaire survey of all individuals fulfilling the criteria of the two sample groups, totalling almost 1500. Previously, a pilot questionnaire study of 21 doctors fulfilling the above criteria was completed.

For the duration of the study, any problems encountered and their subsequent solutions have been logged and documented. All meetings and telephone calls relevant to this have been annotated, and emails and letters stored on file. Records were kept of dates, times and persons contacted regarding difficulties, as well as of all actions being taken by the research team to rectify them.

As the study progressed, two themes began to emerge, namely 'The Data Protection Act' and 'Third parties acting against The Data Protection Act'. The latter refers to the manner in which the fear of the

consequences of failed adherence can affect behaviour, to the extent of imposing restrictions on data which are beyond the Act as it relates to research.

## Results

This section provides an overview of the methodological limitations encountered during the 'Doctors' Career and Retirement Choices' study, resulting from both The Data Protection Act and third parties' fear of acting against it. It also shares the solutions identified to attempt to overcome these.

Consideration of the Data Protection Act by third parties acting as data controllers has resulted in numerous obstructions to obtaining potential participants' contact details for the purposes of this study. Such difficulties encountered include a reluctance to allow the study access to, and use of, university graduate lists held by the department of student services and university 'past students' lists as held by the alumni office. Furthermore, use of doctors' addresses as published by the General Medical Council (GMC) in *The Medical Directory* was disallowed. When making general enquiries with the GMC, it was categorically stated that doctors provide their details through the publication solely for the purpose of enabling patients to check their registration, and not for the use of other health professionals in making contact.

Twelve months of correspondence with individuals at various levels resolved the matter of accessing university lists, and a database of 887 graduates was eventually obtained. As this could have potentially delayed the study, in the interim a 'graduate' purposive interview sample was approached and recruited via email addresses available in the public domain at [www.friendsreunited.co.uk](http://www.friendsreunited.co.uk). Although a rather unorthodox tactic, the site provides the facility to search by graduation year and medical school, so the required sample could be accurately identified. Formal permission was sought to use the information listed to contact potential study participants in this way. The email, which would be sent from The North Western Deanery inviting individuals to contact the study if they would like to participate, was provided to 'Friends Reunited' officials. Permission was granted to the study on condition that a limited number of individuals were contacted in any one instance and no recipients complained of being addressed with 'spam'. Medical graduates responding were then provided with an 'information sheet' before committing to an interview.

As *The Medical Directory* issue could not be rectified, personal networks were used as a strategy to

overcome access problems to inviting individuals over 55 years for interview. This resulted in a purposive sample being identified by the deanery's associate deans, providing a list of friends/colleagues known to fit the required criteria, and whom it was felt may be receptive to the invitation. These individuals received a letter and 'information sheet' from the dean of postgraduate medical studies. These documents informed them of the study, expressed the need for interview participants and explained through whom and how their name and known fulfilment of the criteria for participants had been provided. Those within the sample, who it was recognised had already retired and for whom a current home address was not available, were contacted through their last known NHS department. A cover note was included which emphasised the importance to any other person opening the letter on their behalf, of replying to us if a forwarding address was unknown. This was to enable attempts to contact the addressee through other means, as well as to allow the accurate monitoring of response rates. On occasion, medical staffing departments agreed to forward letters, but only once proof had been given to confirm the identity of the research associate requesting this.

Following the initial difficulties in accessing potential interview participants, further interviewees were recruited to both samples through existing participants, by manner of the 'snowball effect'. Thus each graduate interviewee was requested to pass on the research associate's email to any suitable friends/colleagues not listed on the Friends Reunited website, and all 'over 55' interviewees were asked if they could suggest any friends/colleagues whom the postgraduate dean could also approach by letter.

As postal addresses listed in *The Medical Directory* were also unable to be used to contact the 'over 55' sample with questionnaires, a subscription was purchased for [www.specialistinfo.com](http://www.specialistinfo.com). This website lists practicing consultants' contact details free of charge, for use by patients and other healthcare professionals. It holds the details of approximately 70% of all UK medical consultants and was used to identify 596 North West consultants aged 55 and over to receive questionnaires.

Third parties' had numerous concerns, including anxiety around acting against The Data Protection Act, which made them reluctant to share information with the study and made them exercise rigorous checks with their senior personnel in response to our requests. While significantly less could be done to address this issue, organisations were offered financial reimbursement to cover any costs incurred if they would contact potential participants themselves on the North Western Deanery's behalf. This would have entailed firstly the distribution of letters inviting doctors for interview and later the distribution of questionnaires, and would have avoided the supply

of doctors' personal details to The North Western Deanery. However, neither departments belonging to the university concerned, nor the GMC felt able to agree to this. Fortunately, those solutions already mentioned also resolved this.

## Discussion

The extent of the negative impact of The Data Protection Act upon researchers has not yet become fully apparent. This should not detract from the many benefits which the Act has introduced in protecting individuals' privacy, but perhaps more awareness of its limits and exemptions needs to be promoted. Among those parties with whom this particular study communicated, there was an assumption that The Data Protection Act dictated there to be no sharing of individuals' contact details under any circumstances. Even highlighting the exemption from the Act of data used in research where participants' anonymity is protected in its results, made no difference. This included the research team's referral to relevant sections of The Act which state that personal data may be used under the conditions, (a) that the data are not processed to support measures or decisions with respect to particular individuals, and (b) that the data are not processed in such a way that substantial damage or substantial distress is, or is likely to be, caused to any data subject.

Consequently, in a number of cases where requests and reassurances even from senior members of deanery staff were met with constant resistance, the study team began to consider whether the Act was almost being used as a means of avoiding collation and provision of data needed, especially where this task may have been onerous. This was particularly pertinent in the case of the 'graduate' sample as the North Western Deanery had previously held many of the doctors' details that were being requested, and so the justification for not providing these details was tenuous. These are lists of the region's doctors in training that unfortunately were unable to be used by the deanery's own means to gain a sample, as inevitably graduates from various year groups and medical schools are included, meaning comprehensive details of specified year groups from one particular medical school could not be compiled as necessary.

Following the GMC's insistence that, in view of The Data Protection Act, details provided in *The Medical Directory* could not be used by the study to contact doctors for the purposes of research, such use was investigated. It was possible to gain confirmation that other researchers have used information from *The Medical Directory* in this way, both by contacting them

directly,<sup>2</sup> and via the observation of statements made to this effect in other published works.<sup>3,4</sup>

This thus illustrates how current legislation has the potential to bias research projects and jeopardise their worth if it is allowed. It would seem that, despite the great advance in protecting how information is stored and shared which the Act has brought about, it has in turn threatened to compromise the achievements and value of research and hence the evidence base available to inform good practice. Further analysis would be of great benefit to enable full and more objective comments on this matter, as it is recognised that while the difficulties encountered by the 'Doctors' Career and Retirement Choices' study were diligently recorded, this paper has the weakness of presenting the experiences of only one case study, which may differ from those of others.

There appears to be a lack of literature relating to The Data Protection Act and its use in research, as a search of titles using Medline, The Cochrane Library and CINAHL resulted in only one relevant paper.<sup>5</sup> This supported the 'Doctors' Career and Retirement Choices' study's findings, stating:

There is a need to balance patient confidentiality with the requirement to conduct vital, unbiased research ... The Data Protection Act (1988) is currently being interpreted in a number of different ways. We conclude there is an urgent need for consensus within the health service and academic communities.

This paper found difficulties in two other studies, with difficulties in the recruitment of participants being the main problem shared with the 'Doctors' Career and Retirement Choices' study. Clearly, more work into this area is needed.

## Conclusions

This study demonstrates that while a number of obstacles exist in research that uses medical practitioners as participants, in this particular study the main obstacle has been the difficulties experienced with data protection. A number of the problems encountered would not have occurred prior to recent advancements including the introduction of The Data Protection Act. For example, problems in obtaining and using individuals' details for the purpose of inviting participation in research, would have been less significant. On a positive note, the use of websites to make contact with doctors as well as obtain their postal addresses as a solution, would have been unfounded and uncommon as little as 10 or 15 years ago before the introduction of the internet. Hence this paper highlights some very modern issues and how times are changing for the 21st century researcher.

It can be concluded that while The Data Protection Act has numerous attributes from the perspective of the public, for researchers it has introduced a potential impediment to studies where the recruitment of participants is vital to their advancement and success. From the earliest stages of a study, researchers now need to be aware of, and prepared for, the potential hurdles and time delays posed by this, as well as setting up contingency plans where problems could jeopardise work with rigid time restrictions for completion. Greater and widespread guidance on interpreting the Act is ultimately imperative, as is further investigation into how data protection is impacting upon research across the various fields.

Some of the difficulties discussed here are shared with researchers in other areas of study but a number are specific to medicine. However, as has been demonstrated, most can be overcome with a little determination. It is hoped that as the 'Doctors' Career and Retirement Choices' study continues, its methodological limitations will lessen, but that by sharing its difficulties to date with others, lessons will be learnt and these obstacles avoided elsewhere.

## REFERENCES

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## CONFLICTS OF INTEREST

None.

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